Automated Direct-From-Patient Information Collection For Evidence-Based Diabetes Care

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Background: Computer-based clinical decision support tools can improve physician performance in ambulatory care settings. Acquiring and entering the patient-specific information necessary to take advantage of this technology, however, can often be a major impediment.

Objective: To develop and evaluate a self-administered electronic questionnaire for acquiring patient-specific information to be used for generating diabetes-related evidence-based care recommendations.

Methods: An initial paper questionnaire was developed that evaluated current diabetes management, complications, and screening interventions. This was then coded for electronic presentation using software that can also analyze patient responses and produce personal feedback.

To evaluate the electronic questionnaire, 47 patients completed it using a small laptop computer and also responded to a personal interview that assessed similar topics.

Results: Patients required between 7 - 29 minutes to complete the questionnaire (mean: 15 min.). For 21 of the 23 topics assessed, the agreement between the electronic questionnaire and the personal interview was 80% or higher.

Conclusions: An electronic, self-administered questionnaire can be used to acquire information for generating patient-specific care recommendations.

INTRODUCTION

Diabetes mellitus is a common chronic condition that affects approximately 5% of the population. 10% of these patients have Type I diabetes, while the remaining 90% have Type II diabetes. These patients are known to be at risk of developing acute and chronic complications. The acute complications include severe reactions to either too low or too high blood sugars, while long-standing diabetes significantly increases the risk of both atherosclerotic disease, with its associated cardiac, cerebral and lower limb complications, and microvascular disease, associated with ocular, renal, and neurological complications.

Over the past few years, a number of trials have shown that various interventions can help to prevent these complications and thus decrease the morbidity and mortality associated with diabetes. Non-insulin dependent and insulin dependent diabetics alike benefit from interventions to prevent visual loss, to decrease the mortality associated with established coronary artery disease, and to slow the progression of renal dysfunction. Additional research has demonstrated the beneficial effects of maintaining blood glucose values as close to normal as possible in patients with insulin-dependent diabetes mellitus.

Despite this, there is evidence that many patients do not receive optimal treatment [1]. In diabetes care and numerous other areas of medicine, various physician and patient related factors contribute to this poor compliance with current best evidence, including delayed recognition of complications in their earlier stages [1] and suboptimal patient compliance [2,3].

To address this situation, various different approaches have been developed and tested, including the use of computer-based information systems that match patient-specific characteristics with a knowledge base to produce individualized recommendations. These have been shown to be useful in preventive care,

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ongoing medical care, and in the dosing of potentially toxic medications [4].

To apply this new technology to diabetes care, we are developing several unique tools and resources. These include an automated branching questionnaire that addresses numerous topics relevant to the care of patients with diabetes, software that will generate evidence-based patient-specific recommendations for patients and physicians using information from the automated questionnaire and other sources including laboratory information databases, and a comprehensive database of high quality primary studies and systematic reviews that relate to diabetes care. This paper will focus on the preliminary development and testing of the automated questionnaire.

AN AUTOMATED DIABETES QUESTIONNAIRE

Acquiring patient-specific information necessary for evidence-based decision making in diabetes and other chronic conditions and entering this into an electronic database can be a major impediment to the use of computer-based clinical decision support systems in centres that do not have a well developed electronic medical record and computer terminals in their clinics. To circumvent this, we have developed an automated, branching diabetes questionnaire that patients complete before seeing their health-care professional. The questionnaire acquires information directly from patients relating to their diabetes history, current management, and complications. This information is then used to generate patient-specific evidence-based reminders for diabetes care and general preventive care.

Questionnaire development

Initial development of the questionnaire involved a review of currently available evidence and recommendations relevant to the care of diabetic patients. This included current best research evidence, American Diabetes Association recommendations, Canadian Diabetes Association recommendations, and American College of Physicians guidelines.

The result was a branching set of questions that covers such areas as type and duration of diabetes, current treatment, established complications, previous screening interventions appropriate for patients with diabetes as well as a review of a patient's other cardiovascular risk factors. Several questions relating to general preventive care interventions were also included, based on the current Canadian Task Force on the Periodic Health Examination Guidelines. Each of the questions in the questionnaire either addresses an evidence-based care issue in diabetes, or has been included to facilitate assessment of the current degree of blood sugar control, or assesses the implementation of general preventive care interventions, such as influenza vaccination, that are especially important for patients with chronic diseases.

The questionnaire was initially reviewed in paper form by a group of patients with diabetes and a number of health care professionals involved in diabetes management.

Coding the questionnaire into machine useable format

Subsequently, we coded the questionnaire into a machine useable format using the Surveyor program (previously known as the Guideline Application Program [GAP]). This program, developed by one of us (RH), is a computer-assisted design tool for developing evidence-based automated questionnaires [5]. Surveyor also facilitates the implementation of relatively complex decision algorithms such as those that may be encountered in diabetes care. Computer-based presentation of questionnaires allows self-administration and is efficient and less confusing for patients especially if there are complex branching patterns, as is the case for diabetes where only a subset of the questions will apply to any one patient, depending on their gender, age, the type and duration of their diabetes, and any complications that they may have experienced to date. Further, patients tend to be more candid with computers than with live interviews concerning sensitive personal matters such as risky behaviors and sexual function [6].

Initial evaluation of the automated diabetes questionnaire

After developing an initial automated version of the diabetes questionnaire, we presented it to 13 diabetic patients from the Diabetes Care and Research Centre (DCRC) at McMaster University using a specially designed computer known as the HealthQuiz system. Health-Quiz

represents a unique patient-interface format that was partially developed at McMaster University (in cooperation with teams in Chicago and Baltimore, as well as the Nellcor corporation). It is a very light lap-top device with a display screen and three buttons for inputting responses to questions (yes, no, or unsure). This system had previously undergone extensive patient acceptability testing [7].

The involvement of these initial 13 patients demonstrated the acceptability of an automated questionnaire to patients with diabetes. The patient ages encompassed a wide range from 30 - 70 years. Detailed interviews of the patients after completion of the questionnaire, in conjunction with forms summarizing the patients' responses, demonstrated the accuracy of the majority of the information provided. Patients were asked to express any concerns they had regarding the terminology, content, or general flow and logic of the questionnaire. Overall, the patients were very pleased with the experience. Several questions, however, were confusing to the patients we interviewed. These, along with any other suggestions for improvements, were used to revise the initial questionnaire.

Comparing the automated diabetes questionnaire with a personal interview

To further evaluate the diabetes questionnaire, the patient responses to the automated questionnaire have been compared to information gathered during a structured personal interview. Consecutive patients with out-patient clinic appointments at the Diabetes Care and Research Centre were invited to participate in the study and consenting patients were subsequently seen by a research assistant. During each session, patients were asked to complete both the automated diabetes questionnaire and a structured interview with the research assistant that assessed many of the topics included in the computer questionnaire. The order of administration was randomized. In addition, the total time required by patients to complete the automated questionnaire was recorded.

To analyze the results, responses from the automated questionnaire and personal interview were initially coded in a blinded fashion. The absolute agreement for each question was then evaluated along with the chance-corrected agreement (Kappa) using quadratic weights. Total agreement between the two forms of administration as a whole was not evaluated because the questionnaire consists of numerous separate topics, rather than including numerous questions that address different aspects of a single entity.

RESULTS

47 patients consented and competed both the automated questionnaire and the personal interview. The ages of the patients ranged from 23 - 76 (mean: 57; SD: 13.6). The average time taken to complete the automated questionnaire was 15 minutes (range: 7 - 29; SD: 6.1). Absolute agreement for the 23 topics varied from 60% - 100% (see Table), with 2 topics having an agreement of less than 80%. The order of administration did not affect the level of agreement.

Disagreements represented 7.5% of all possible response pairs. The majority of these were minor differences or overly conservative responses to the automated questionnaire suggesting that appropriate interventions had not recently been carried out when in fact they had been completed. 17 major disagreements (1.6% of all possible response pairs) occurred. These included 7 cases where responses to the automated questionnaire suggested that appropriate retinopathy or nephropathy screening had occurred within the past year while this was not reported to be the case during the interview. In 6 cases, the automated questionnaire answers did not indicate hypoglycemic or hyperglycemic symptoms that were noted during the interview.

The response "Unsure" was infrequent except for a question relating to a patient's last urinalysis examination for proteinuria. 43% of patients indicated "Unsure" for this question both when completing the automated questionnaire and during the personal interview.

DISCUSSION

These results support a hypothesis that diabetes-related information can be collected directly from patients in a short period of time using an electronic questionnaire. The study also confirms the importance of testing new diagnostic tools. The poor agreement for several topics suggests that a few questions will need to be re-phased, and the high frequency of

"Unsure" responses to the questions relating to proteinuria indicate that this topic should be excluded completely from the patient questionnaire.

Subsequent development of the diabetes clinical decision support system will involve several steps. These will include the development of tools to allow information from other sources such as laboratory information systems to be accessed. Such information will be complementary to the patient questionnaire responses.

Evidence-based feedback forms for both patients and physicians are also being developed. Using software routines available within the Surveyor program, patient-specific information will be combined with current best evidence to allow for the provision of individualized recommendations for treatment and screening purposes. Such feedback will serve several purposes. First of all, it is likely to improve the level of compliance with current diabetes health-maintenance recommendations. Both interventions directed towards physicians and interventions directed towards patients have been shown to increase the rate at which necessary health care maneuvers are performed. For example, numerous studies have evaluated the impact of computer-based patient-specific feedback on physician performance in the area of preventive care [4]. These studies evaluated the role of reminders in such diverse areas as vaccinations, blood pressure assessments, and cancer prevention interventions. Lobach and colleagues [8] noted improved compliance with diabetes care recommendations in their randomized trial.

Other studies have evaluated the role of patient-mediated interventions. A recent systematic review [9] found that 7 of 9 studies evaluating such patient-mediated interventions showed a benefit in terms of physician performance. When such interventions were combined with reminders to physicians, benefits were noted in 3 of 4 studies.

Also, providing patients with feedback is expected to be beneficial because it may increase patient participation during the appointment which has been shown to improve patient health outcomes. Work by Greenfield and colleagues [10] demonstrated improved glycemic control when patients were encouraged to discuss issues with their physicians. Rost and colleagues [11] noted that patients reported fewer limitations in activities of daily living if patients participated in an intervention designed to increase question asking during the medical appointment.

The feedback forms will also inform patients about how they can access additional information from the database of diabetes-related evidence that is being assembled as part of the diabetes support system. This will provide patients with the opportunity to become familiar with the underlying reasons for any recommendations that have been made for them.

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Table: Topic-specific agreement between automated questionnaire and personal interview.

Number	Topic	Absolute agreement (%)	Kappa (%)
1	Duration of diabetes.	89	75
2	Initial requirement for insulin.	100	100
3	Initial treatment with oral hypoglycemics.	91	82
4	Current insulin regime.	94	98
5	Current use of glyburide.	98	95
6	Current use of metformin.	100	100
7	Current use of other oral hypoglycemics.	98	80
8	Current blood glucose self-monitoring practices.	68	54
9	Time since last retinal examination.	80	19
10	Time since last 24-hour urine collection for microalbuminuria.	91	98
11	Time since last urinalysis test.	86	93
12	Feet examination practices.	83	84
13	Recent hypoglycemic symptoms.	93	83
14	Recent hyperglycemic symptoms.	60	23
15	History of requiring help from others because of hypoglycemia.	96	90
16	History of hypertension.	96	91
17	Previously noted to have hypercholesterolemia.	88	75
18	Current smoker.	100	100
19	Previous myocardial infarction.	100	100
20	History of angina.	100	100
21	History of stroke or transient ischemic attack.	100	100
22	Currently taking acetylsalicylic acid (ASA).	96	90
23	Influenza vaccination status.	100	100

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